



# GREATER CHOICE AND CONTROL?

## PARENT/CARER VIEWS ON PERSONAL HEALTH BUDGETS FOR DISABLED CHILDREN WHO USE REHABILITATION SERVICES.

### AIM OF THIS POSTER

The aim is to report on the responses of parents interviewed about the prospect of using a personalised health budget for their children with regard to rehabilitation therapy, at a time of cuts to child health services (British Academy of Childhood Disability & British Association for Community Child Health 2014). The results reported here are part of a project on the experiences of parents of children who use rehabilitation services.

### METHODS

Nine parents and primary carers of disabled children (aged 18 years or younger) from one region in the South of England who accessed at least 2 paediatric rehabilitation therapy services locally (e.g. physiotherapy, occupational therapy, and speech and language therapy) were recruited. Focus group and face-to-face interviews lasted for 1 hour, telephone interviews were shorter (30-45 minutes). Interview data was transcribed, entered into NVIVO and analysed using 'framework analysis' (Pope & Mays 2006).

### RESULTS

Parent views on the plans of personal budgets were shaped by their extensive experience with health and care services. Their views were differentiated and nuanced about the prospects and limits of what a financial package, like a personal budget, could offer them.

#### THEME 1 ENTITLEMENT

None of the parents interviewed had experience of a personal health budget or knew if they were entitled to one. There was lack of awareness about what a personal budget was, how it could be used or who would be eligible.

*'I don't know if it's only very profoundly disabled children who are entitled to that budget or quite how that works, and no one's ever suggested that I would be entitled to a budget.'* (Parent 06)

#### THEME 2 POTENTIAL BENEFITS

When asked to imagine how a personal budget might work for them, parents said they wanted to purchase additional specialist services, particularly services that are not available through local NHS health services, non-traditional and alternative therapies. They also thought that they may be able to 'buy' access to services more quickly for which are currently waiting times.

*'In some ways is quite useful because it would allow me to pay for some of the private services that I'm already buying'* (Parent 09).  
*'There could be, as you say, hydrotherapy or it could be some other kind of therapy that he needs that I can't get [on the NHS]'* (Parent 08).  
*'You would hope then because you have more control that you would get those bits quicker. I would want to keep what I have but just hopefully like when it comes to equipment then it could be faster'* (Parent 03).

#### THEME 3 DRAWBACKS

Parents did not want to 'lose out' if they opted for a personal health budget. Some were concerned that the funding through the personal budget should be at least equivalent to the level of the current services they received.

*'If I was given the option to choose, I'd want to know on a quantified basis what's the value of the services that I'm receiving. .... If I had the pot of cash ... to control it myself, my first question would be does my pot of cash allow me to have the exact same service I've got now?'* (Parent 09).  
*'Maybe it depends how much everything costs as well and if you've got enough in your budget to pay for those things that are important.'* (Parent 03).

#### THEME 4 MANAGING A BUDGET

Parents expected that a personal budget would involve taking on additional responsibility. Some questioned whether they either were able or would want to do this when they were already busy organising care and services on behalf of their child. Others felt that they didn't have the necessary knowledge or expertise to know how to use a budget or what to purchase.

*'You know, I'm busy enough already. If I've then got to arrange for her physiotherapy and her occupational therapy and so on, you know...'* (Parent 01)

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### WHAT IS A PERSONAL HEALTH BUDGET?

- The 'person centred' alternative to generically provided services.
- Intended to provide greater flexibility to purchase elements of personalised care.
- Available to those with Education Health and Care Plans since 2014. (NHS England, Patient Participation Team 2014).

*'...an amount of money identified by the local authority to deliver all or some of the provision set out in an Education Health & Care Plan (EHCP)'.* UK Children and Families Act (2014)

### SUMMARY AND CONCLUSION

- Parent/carer consideration about personal health budgets was informed by individual experiences of current provision and their 'history' of receiving care generally.
- Where parent/carers perceived benefits (additional services/shorter wait times) these were weighed against drawbacks (responsibility/ uncertainty).
- The current 'imperfect' system provided parent/carers with certainty, reliability and a comprehensive service. There were concerns that personalised care may lead to uneven provision and a reduction in certain services.

### RECOMMENDATIONS

- Parent/carers need more information about personal health budgets including entitlement and eligibility criteria if the original aim of transforming services & responding to parental preferences and choice is to be realised (Slasberg & Beresford 2017).
- Policy makers and commissioners need to engage with carers at an early stage to ensure that the provision they offer meets the needs and expectations of this knowledgeable group of service users.

### LIMITATIONS OF THE STUDY

This was an exploratory study based on a small number of participants, the findings do not present a generalizable picture of the viewpoints of parents and carers. Parents who participated in the study shared their views and gave their time enthusiastically. As experts in managing the care of their children, their views provide a ground level insight into the expectations and concerns about the implementation of personal budgets.

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